



Draft

Provisional Health of Disabled People Strategy

2023

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Citation: Ministry of Health. 2023. Provisional Health of Disabled People Strategy. Wellington: Ministry of Health.

Published in July 2023 by the Ministry of Health
PO Box 5013, Wellington 6140, New Zealand

ISBN XXXXX (print)
ISBN XXXXX (online)
HP XXXX



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Minister's Foreword

As Minister of Health, I am honoured to present the Health of Disabled People Strategy: the first dedicated, health system-led strategy for disabled people in Aotearoa New Zealand.

The Health of Disabled People Strategy (the strategy) sets the direction and long-term priorities to move towards achieving equity in disabled people's health and wellbeing outcomes over the next ten years. The strategy will contribute to the transformation of the health system by providing a framework to guide health entities to improve disabled people's health and wellbeing outcomes in Aotearoa New Zealand.

The strategy gives effect to Te Tiriti o Waitangi | the Treaty of Waitangi and is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It also builds upon and draws from other work, such as the New Zealand Disability Strategy 2016-2026 and Disability Action Plan, Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan, the Healthy Ageing Strategy 2016 and Enabling Good Lives.

We know that disabled people experience poorer health and wellbeing, including both physical and mental health outcomes, compared to non-disabled people. Inequities in health outcomes are acutely felt by specific communities within the broader disabled population, particularly tāngata whaikaha Māori. Despite this, disabled people and their whānau continue to demonstrate their strengths and resiliencies in advocating for and meeting their own health and wellbeing needs, especially when the health system has failed to do so.

This strategy was developed following face-to-face, online and written engagement with disabled people and their whānau. Through engagement, we heard the importance of an equitable, accessible and culturally safe health system for disabled people and their whānau that enables autonomy and agency. We also heard that the health and wellbeing of disabled people and their whānau includes broader factors, such as housing and education. These insights led to the shaping of the Health of Disabled People Strategy's five priority areas. I recognise and sincerely thank everyone who shared their valuable contributions.

The strategy is being published in a provisional form to allow for further targeted engagement with the disability community and further shaping of priorities, as we continue to shift the health system towards achieving pae ora | healthy futures for disabled people and their whānau.

I acknowledge that there is more to do to achieve this vision for disabled people and their whānau. The Health of Disabled People Strategy offers a strategic pathway to ensure that we are moving in the right direction.

Hon Dr Ayesha Verrall
Minister of Health

Acknowledgements

Our gratitude and acknowledgements to the disabled people, whānau, groups, communities and organisations that have shared or gathered insights, experiences and aspirations of the health and wellbeing of disabled people with the Crown for many years, including through the engagement on the Pae Ora strategies.

The contribution from each individual, whānau, group, organisation and community in this process is greatly appreciated.

We acknowledge all who continue to advocate for healthier futures for disabled people and their whānau in Aotearoa New Zealand.

Glossary

Disability	Includes long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder the full and effective participation of disabled people in society on an equal basis with others (United Nations Convention on the Rights of Persons with Disabilities).
Disability community	Includes disabled people, whānau/families, partners, friends, relatives, unpaid carers, and others directly involved in informal support as determined by disabled people. This includes advocacy/consumer organisations made up of and representing disabled people (Office for Disability Issues 2022).
Tāngata whaikaha Māori	An umbrella term to refer to Māori who are disabled and their whānau (including whānau hāpai). Whaikaha means to have strength, to have ability, and to be enabled. ¹
Tagata sa'ilimalo	The term 'tagata sa'ilimalo', in lower-case form, is a term of identity to replace 'Pacific disabled people, their families, and carers' (Tōfā Mamao 2022).

¹ In 2016, as a founding member of the Māori Disability Leadership Group, Maaka Tibble is quoted saying "Tāngata Whaikaha means people who are determined to do well, or is certainly a goal that they reach for. It fits nicely with the goals and aims of people with disabilities who are determined in some way to do well and create opportunities for themselves as opposed to being labelled, as in the past."

Executive Summary

The Health of Disabled People Strategy is one of six health strategies required under the Pae Ora (Healthy Futures) Act 2022. The five other strategies are the New Zealand Health Strategy, Hauora Māori Strategy, Te Mana Ola - The Pacific Health Strategy, Women's Health Strategy and Rural Health Strategy. Together, these strategies provide a framework for achieving pae ora | healthy futures for all New Zealanders.

The Health of Disabled People Strategy sets the direction and long-term priorities to move towards achieving equity in disabled people's health and wellbeing outcomes over the next ten years. The strategy gives effect to Te Tiriti o Waitangi | the Treaty of Waitangi and is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It also builds upon and draws from other work, such as the New Zealand Disability Strategy 2016-2026 and Disability Action Plan, Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan, the Healthy Ageing Strategy 2016 and Enabling Good Lives (EGL).

This strategy was developed following engagement with disabled people and their whānau, an assessment of disabled people's health outcomes and health sector performance, and a view of population health trends. The strategy is being published in a provisional form to allow for further targeted engagement with the disability community and further shaping of priorities.

Disabled people make up a significant and diverse part of Aotearoa New Zealand. In 2013, a total of 1.1 million people (24 per cent of the population) were identified as disabled (Statistics New Zealand 2014). Disabled people experience poorer health, including both physical and mental health outcomes, compared to non-disabled people. Inequities in health outcomes are acutely felt by specific communities within the broader disabled population, particularly tāngata whaikaha Māori, as well as tagata sa'ilimalo and disabled people from rainbow communities.

The Health of Disabled People Strategy identifies five key priority areas for the health system to focus on to achieve pae ora | healthy futures for disabled people and their whānau:

- **Priority 1:** Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.
- **Priority 2:** Ensure the health system is designed by and accessible for disabled people and their whānau, and provides models of care that suit their needs.
- **Priority 3:** Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.
- **Priority 4:** Build health workforce capacity and capability to meet the needs of disabled people and their whānau.
- **Priority 5:** Increase the visibility of disabled people in health data, research and evidence, as part of an active learning system.

Implementation and monitoring of the Health of Disabled People Strategy will include setting shorter term priorities for the Government Policy Statement and New Zealand Health Plan which link to strategic objectives, and further targeted engagement with the disability community to develop a finalised strategy.

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Provisional Health of Disabled People Strategy

Purpose

To set the direction and long-term priorities to achieve equity in disabled people’s health and wellbeing outcomes over the next ten years.

Vision

Pae ora (Healthy Futures) for disabled people and their whānau

Strategic Alignment

- Te Tiriti o Waitangi
- UNCRPD
- Pae Ora Act 2022
- NZ Disability Strategy 2016 -26

Current state

- 1.1 million people are identified as disabled (24% of Aotearoa New Zealand’s population). 370,000 are aged 65 years or over.
- Māori and Pacific peoples have higher disability rates than non-Māori, non-Pacific people.
- Disabled people have higher mortality and lower life expectancy than non-disabled people.
- Disabled people experience higher rates of unmet need for health care due to cost and transport.

Engagement and Development

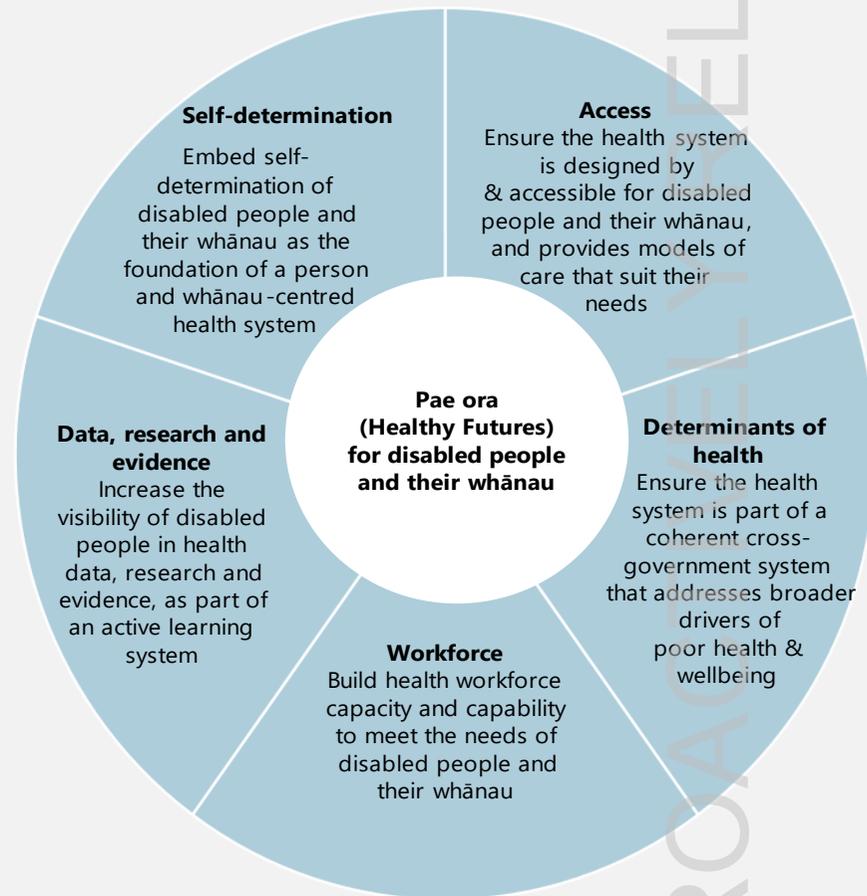
We developed the priority areas through analysis of:

- approximately 29 meetings and workshops with disabled people and their whānau
- over 50 written submissions
- existing engagements between disabled people and their whānau and the Crown.

Themes from engagement

- Disabled people want to be heard in the health system and in control of their own health.
- Tāngata whaikaha Māori & their whānau want the health system to be more responsive to their needs and aspirations.
- Disabled people and their whānau want better access to supportive, community -based primary and preventative care.
- Disabled people and their whānau want a health system that facilitates access to wider services and supports to address broader drivers of poor health and wellbeing.
- Disabled people want to see themselves represented in a health workforce that is better equipped to meet their health and wellbeing needs.
- Disabled people want to be visible in the health system.

Priority areas for the health system



Introduction

Purpose of the Health of Disabled People Strategy

We are children, young people and adults, we are parents and grandparents. We are also friends, family and whānau. What we want is no different to anyone else in New Zealand; we want to belong, contribute to our families and whānau and participate in our communities. We are 1.1 million New Zealanders, and we represent almost a quarter (24 percent) of New Zealand's population. (New Zealand Disability Strategy 2016-2026).

The Health of Disabled People Strategy is the first dedicated, health system-led strategy for disabled people in Aotearoa New Zealand. It sets the direction and long-term priorities to move towards achieving equity in disabled people's health and wellbeing outcomes over the next ten years. The strategy will contribute to the transformation of the health system by providing a framework to guide health entities² to improve disabled people's health and wellbeing outcomes in Aotearoa New Zealand.

The Health of Disabled People Strategy is one of six health strategies required under the Pae Ora (Healthy Futures) Act 2022 (Pae Ora Act). The Pae Ora Act lays the foundation for the transformation of our health system to support all New Zealanders to live longer and have the best possible quality of life through:

- protecting, promoting, and improving the health of all New Zealanders
- achieving equity in health outcomes among Aotearoa New Zealand's population groups, including by striving to eliminate health disparities for Māori
- building towards pae ora | healthy futures for all New Zealanders.

The strategy builds on and reflects the higher-level priorities set in the Hauora Māori Strategy and the New Zealand Health Strategy.

The Health of Disabled People Strategy sets out priorities for improvements in health and wellbeing, including accessible and community-based primary and preventative services, addressing the broader determinants of health³ and health workforce development.

² Section 4 of the Pae Ora (Healthy Futures) Act 2022 defines 'health entities' as Te Whatu Ora/Health New Zealand, Health Quality and Safety Commission, Te Aka Whai Ora/Māori Health Authority, Pharmac and the New Zealand Blood and Organ Service.

³ The broader determinants of health are a range of social, economic, and environmental factors that represent the wider forces in the environments in which people are born, grow up, live, learn, work and age that have a significant influence on health and wellbeing outcomes (Ministry of Health 2023a).

The priorities were developed through engagement with disabled people and their whānau, an assessment of disabled people's health outcomes and health sector performance, and a view of population health trends. We received over 50 written submissions and engaged in approximately 29 meetings and workshops with disabled people and their whānau.

This strategy is being published in a provisional form to allow for further targeted engagement with the disability community and further shaping of priorities.

The structure of this strategy

- **Part 1** describes a long-term vision for the health of disabled people and identifies the key drivers underpinning the vision.
- **Part 2** provides an assessment of the current state of the health of disabled people and the health system itself, drawing on engagement carried out to develop this strategy.
- **Part 3** identifies the priority areas in which changes are needed to achieve our vision and indicates the types of change required over the next ten years.
- **Part 4** describes the next steps for how these changes can be delivered, including how the strategic direction will be translated into actions for entities.

Part 1: Our vision of pae ora | healthy futures for disabled people and their whānau

What is our vision?

Our vision is to achieve pae ora | healthy futures for disabled people and their whānau in Aotearoa New Zealand. This is a future in which all disabled people and their whānau live long, fulfilling and more independent lives in good health.

Pae ora is a holistic concept of health and wellbeing. This means that it considers all the broad factors and contexts that influence people's health and wellbeing throughout their life.

Achieving pae ora | healthy futures means that disabled people and their whānau are part of healthy and inclusive communities, live in environments that enhance their quality of life, and are supported to maintain their health and wellbeing. This support will be provided by an equitable and fully accessible health system that considers all factors that influence the health and wellbeing of disabled people and their whānau.

To achieve this vision, we must work collaboratively with disabled people and their whānau, with iwi, hapū and Māori communities, Pacific communities, other communities our health system serves, and with the wider organisations and agencies that contribute to the health and wellbeing of disabled people and their whānau.

Who is this strategy for?

This strategy is for all who identify as, or provide support to, disabled people⁴ in Aotearoa New Zealand. It is also for those who may not identify as disabled but can see their lived experiences reflected in the strategy.⁵

⁴ This strategy uses the term 'disabled people' in alignment with the New Zealand Disability Strategy 2016-2026. We acknowledge that other terms, including 'people with disability' are preferred by some people.

⁵ For example, we acknowledge that many Deaf people identify as being part of the Deaf community and do not always identify as being disabled. People with disabling mental health conditions may identify as part of the mental health community, and not the disability community (Office for Disability Issues 2016).

The strategy acknowledges that for both tāngata whenua and tāngata Tiriti, the health system approach to disability is something experienced both by the individual, and by the wider whānau, family and support networks.

Whānau, family and wider support networks play a vital role in supporting and making real a disabled person's independence and aspirations. The term disabled people and their whānau is used throughout to encapsulate this collective approach to disabled people's health. The strategy also recognises the overlap between disability and ageing for both individuals and their whānau.

This strategy uses the term 'tāngata whaikaha Māori' as an umbrella term to refer to Māori who are disabled and their whānau (including whānau hāpai).⁶ Whaikaha means to have strength, to have ability, and to be enabled.⁷ We acknowledge that other terms are used by tāngata whaikaha Māori and their whānau, including whānau hauā. This strategy includes Māori defined terminologies that reflect, strengthen, and validate Māori cultural identity, language, values, principles, practices, lineages, and linkages to the land.

Our commitment to Te Tiriti o Waitangi

The health sector is committed to fulfilling the special relationship between Māori and the Crown under Te Tiriti o Waitangi | the Treaty of Waitangi (Te Tiriti). Regarding the text of Te Tiriti and declarations made during its signing – the Crown, as the kaitiaki and steward of the health system (under article 1 of Te Tiriti), has the responsibility to enable Māori to exercise authority over their health and wellbeing (under article 2) and achieve equitable health outcomes for Māori (under article 3) in ways that enable Māori to live, thrive and flourish as Māori (Ritenga Māori declaration).

The Crown's approach to meeting its obligations under Te Tiriti is outlined in section 6 of the Pae Ora (Healthy Futures) Act 2022. The legislation contains specific provisions intended to give effect to the Crown's obligations.

In particular, the health sector principles in section 7 of the Pae Ora Act guide the Minister of Health, Manatū Hauora | the Ministry of Health and all health entities in how they carry out their functions. The health sector principles incorporate key outcomes and behaviours derived from the principles of Te Tiriti, as articulated by the courts and the Waitangi Tribunal, including:

- **Tino rangatiratanga:** Providing for Māori self-determination and mana motuhake in the design, delivery and monitoring of health services.

⁶ The term Tāngata Whaikaha is used in *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*, and is included as part of *Te Reo Hāpai (The Language of Enrichment)*, a Māori language glossary for use in the mental health, addiction and disability sectors (Te Pou o Te Whakaaro Nui 2020).

⁷ In 2016, as a founding member of the Māori Disability Leadership Group, Maaka Tibble is quoted saying "Tāngata Whaikaha means people who are determined to do well, or is certainly a goal that they reach for. It fits nicely with the goals and aims of people with disabilities who are determined in some way to do well and create opportunities for themselves as opposed to being labelled, as in the past."

- **Equity:** Being committed to achieving equitable health outcomes for Māori.
- **Active protection:** Acting to the fullest extent practicable to achieve equitable health outcomes for Māori. This includes ensuring that the Crown, its agents and its Treaty partner under Te Tiriti are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity.
- **Options:** Providing for and properly resourcing kaupapa Māori health services. Furthermore, the Crown is obliged to ensure that all health services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.
- **Partnership:** Working in partnership with Māori in the governance, design, delivery and monitoring of health services – Māori must be co-designers, with the Crown, of the primary health system for Māori.

These principles⁸ are central to achieving our vision of pae ora | healthy futures for Māori. Pae ora has a special meaning for Māori, and includes three inter-connected elements (**Appendix One** provides more fulsome definitions):

- **Mauri ora (healthy individuals)** seeks to shift the mauri (or life force) of a person from one that is languishing to one that is flourishing.
- **Whānau ora (healthy families)** is a fundamental philosophy for creating strong, healthy and empowered whānau. A strong, healthy and empowered whānau can make the most significant difference to Māori health and wellbeing.
- **Wai ora (healthy environments)** acknowledges the importance of Māori connections to whenua as part of the environments in which we live and belong – and the significant impact this has on the health and wellbeing of individuals, whānau, hapū, iwi and Māori communities.

Our commitment to Te Tiriti o Waitangi and priorities for hauora Māori are described in greater detail in the Hauora Māori Strategy published in parallel with this document.

Wider strategic and international context underpinning the vision

This strategy is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Aotearoa New Zealand ratified in 2008. The strategy uses a social model approach to disability. It also builds upon and draws from other work, such as the New Zealand Disability Strategy 2016-2026 and Disability Action Plan, Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan (Whāia Te Ao Mārama), the Healthy Ageing Strategy 2016 and Enabling Good Lives (EGL).

⁸ The principles were recommended in the Waitangi Tribunal's *Hauora* report (Waitangi Tribunal 2019).

The UNCRPD describes disability as including long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder the full and effective participation of disabled people in society on an equal basis with others.

This social model approach to disability maintains that it is environments and attitudes that disable people with impairments, not the impairment itself. By adopting a social model approach to disability in the Health of Disabled People Strategy, we are seeking to move towards a health system that supports a rights-based approach to health service delivery and considers all factors that influence people's health and wellbeing. We also recognise that the health system itself can be disabling for disabled people and seek to move towards a system that is enabling.

The EGL principles underpin this strategy, focusing on the principles of self-determination, early intervention (focusing on preventative care in the community for individuals and whānau), and supporting an aspirational approach for adults and children through a health system that works to support these aspirations. This approach aligns with that of Whāia Te Ao Mārama.

What does meeting this vision look like for disabled people and their whānau?

Achieving the vision of pae ora | healthy futures for disabled people and their whānau means that disabled people and their whānau have voice, choice, and independence in their health care. Specifically:

- the experiences and voice of disabled people and their whānau are heard, respected, and validated by health professionals and decision-makers
- people have autonomy and agency over their health, wellbeing, and care
- the health system is easy to navigate and access, with support for disabled people and whānau to access services where needed. This includes health services specific to disability as well as all other health services
- the health system is part of a broader cross-government system that provides person and whānau-centred support to address all elements of disabled people's health and wellbeing needs throughout their life
- there is a representative and culturally and disability competent workforce that is continually supported to provide rights-based care for disabled people. This workforce is a safe, inclusive and flexible employer of disabled people
- disabled people see themselves represented in health system data, research and evaluation.

Part 2: Where are we now?

What does health and wellbeing look like for disabled people and their whānau?

Disabled people make up a significant and diverse part of Aotearoa New Zealand

In 2013, 24 per cent of the Aotearoa New Zealand population were identified as disabled (a total of 1.1 million people). Of this (Statistics New Zealand 2014)⁹:

- people aged 65 or over were much more likely to be disabled (370,000 people, representing 35 percent of the disabled population)
- Māori and Pacific peoples had higher disability rates than non-Māori, non-Pacific people
- for adults, physical limitations were the most common type of impairment
- for children, a learning difficulty was the most common impairment
- just over half of all disabled people had more than one type of impairment
- an estimated 242,000 people (5% of New Zealanders) are living with a disability caused by psychological and/or psychiatric conditions
- rainbow communities have a higher proportion of disabled people than the non-rainbow population (Statistics New Zealand 2022a).

Disabled people experience poorer health and wellbeing outcomes

Disabled people consider themselves overall to be in poorer health compared to non-disabled people. Evidence shows that:

- disabled people experience poorer health outcomes, have higher rates of mortality and lower life expectancy compared to non-disabled people (Ministry of Health 2011; Ministry of Health 2021)
- disabled people have reported very poor mental health, including high or very high levels of psychological distress, and have unmet mental health needs (Government Inquiry into Mental Health and Addiction 2018; Ministry of Health 2022a)

⁹ The Disability Survey: 2013 identified disability through a series of questions that asked whether a person had difficulty doing certain activities, and if the difficulty was long term (lasting six months or more). This included questions asking if a person had difficulty hearing, seeing or walking, and to what degree. We note that these questions are about functional impairment, rather than self-identified disability, which does not align with the social model of disability.

- adults with physical impairments experience a higher prevalence of chronic diseases¹⁰ (Health and Disability System Review 2020; Te Pou o Te Whakaaro Nui 2013)
- people with long-term mental health conditions report poorer health-related quality of life (Wheeler et al 2015)
- disabled people's use of health services is generally at least double that of the non-disabled population, regardless of age or impairment (Health and Disability System Review 2020).

Inequities in health outcomes are acutely felt by specific communities within the broader disabled population. For example:

- tāngata whaikaha Māori and tagata sa'ilimalo report higher levels of unmet health need (Russell et al 2022)
- disabled young people report experiencing higher rates of mental distress, poorer self-ratings of health and higher rates of inability to access health care than non-disabled young people (Department of the Prime Minister and Cabinet 2019)
- older people have much higher rates of long-term chronic health conditions and other impairments that require support on a daily or regular basis (Ministry of Health 2016)
- disabled rainbow young people reported poorer health and wellbeing, particularly mental health, than other population groups (Roy et al 2021)
- children and young people with impairments known to Oranga Tamariki have more frequent health service interactions, potentially avoidable hospitalisations, emergency department contact and mental health service contact or treatment (Oranga Tamariki 2020)
- people with intellectual disability experience lower life expectancy, higher rates of specific health conditions (including coronary heart disease, diabetes and chronic respiratory disease), and higher use of health services (apart from preventative screening services) than people without intellectual disability (Ministry of Health 2011; Health and Disability System Review 2020).

Poor health and wellbeing outcomes for disabled people and their whānau are driven by broader determinants of health

The experiences of discrimination and other broader determinants of health, including housing conditions, employment and education, impact heavily on the health and wellbeing of disabled people. Some of these broader determinants are:

¹⁰ Including arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol and stroke.

Socioeconomic deprivation ¹¹	<ul style="list-style-type: none"> • Disabled people are more likely to experience socioeconomic deprivation than non-disabled people (Brennan 2016; Convention Coalition Monitoring Group 2015). Poverty can prevent access to health services and information, as well as to food and housing, and can negatively impact physical, mental and emotional health and wellbeing. • Growing up in poverty has long-term detrimental impacts on children. Disabled children are more likely to be living in poverty and experience material hardship than non-disabled children (Statistics New Zealand 2021; Statistics New Zealand 2023). • Children living in a household where someone (child or adult) has a disability are more likely to be living in poverty than children living in a household where no one has a disability (Statistics New Zealand 2023). • Disabled people are less likely than non-disabled people to eat the recommended number of vegetables and fruit per day and are less likely to be physically active (Ministry of Health 2022a).
Ableism ¹² and stigma	<ul style="list-style-type: none"> • This is experienced by disabled people across all facets of life, which affects physical and mental health, and overall wellbeing (World Health Organisation 2023). • The health system has historically been designed by non-disabled people, for non-disabled people. The attitudes of health sector workers towards disability can result in disabled people receiving poorer quality care in the health system and experiencing poor health and wellbeing outcomes.
Intersecting discrimination, including racism and sexism	<ul style="list-style-type: none"> • This drives ongoing disadvantage and poor health outcomes, particularly for tāngata whaikaha Māori. • Disabled women can face intersecting forms of discrimination relating to gender and disability, as well as other intersecting factors such as age, language, ethnicity and religion (YWCA 2019). • Disabled people from rainbow communities can face specific forms of discrimination, such as transphobia and homophobia, alongside ableism, racism and other forms of discrimination.
Social exclusion	<ul style="list-style-type: none"> • Disabled people experience greater social exclusion and have lower levels of community participation than non-disabled peers. This can be due to barriers such as inaccessible community facilities and transport systems.

¹¹ Socioeconomic deprivation is defined as falling below the adequate standard of living according to the majority of society (Robinson et al 2017). DEP-17 is a well-established deprivation index developed by the Ministry of Social Development for Aotearoa New Zealand.

¹² Ableism is discrimination against disabled people based on disability. It ranges in scale from small microaggressions and offensive stereotypes through to systemic ableism. Many ableist stereotypes and beliefs are deeply ingrained in society and are subconsciously internalised (Office for Disability Issues 2022).

	<ul style="list-style-type: none"> • Social exclusion can result in lower rates of participation in sports, exercise, and wider community activities (Cockburn and Atkinson 2018; Mirfin-Veitch et al 2012).
Family violence and sexual violence	<ul style="list-style-type: none"> • Rates of violence towards disabled people are much higher than those towards non-disabled people, and impact on health and wellbeing (Fanslow et al 2021; Ministry of Justice 2021; Te Puna Aonui 2022). • Family and sexual violence can also result in impairments, including traumatic brain injury, mental health conditions and physical impairments (New Zealand Family Violence Clearinghouse 2019).
Housing	<ul style="list-style-type: none"> • Disabled people are more likely to live in poor housing conditions, and consequently have higher rates of potentially avoidable housing-related hospitalisations (Howden-Chapman et al 2021). • One in six people with a physical impairment has an unmet need for some kind of modification to their home (Statistics New Zealand 2014). • Disabled people have felt they have limited choice when trying to access adequate housing, including limited choice over where and who they live with. This negatively impacts wellbeing and quality of life (Donald Beasley Institute 2020). • The rising costs of rental accommodation leave limited funds to meet basic needs, including health care.
Digital inclusion	<ul style="list-style-type: none"> • Widespread digital inclusion of disabled people online likely leads to improved independence, engagement with the workplace, and connection with people online, all of which can benefit wellbeing (Department of Internal Affairs 2020). • Disabled people are more likely than non-disabled people to have low access to the internet. This has been associated with lower subjective wellbeing than those who do have access (Grimes and White 2019).
Income and employment	<ul style="list-style-type: none"> • Disabled people are far less likely to be employed than non-disabled people, and when employed, their weekly incomes are lower than those of other groups (Statistics New Zealand 2019; Statistics New Zealand 2022b). This impacts their financial wellbeing, and they may become solely reliant on superannuation¹³ as their source of income when older. It also impacts overall health and wellbeing due to financial stress. • Disabled children are more likely to be in households that have low incomes and that report having just enough or not enough money (CCS Disability Action 2019; Statistics New Zealand 2021).

¹³ If they meet the eligibility criteria for New Zealand Superannuation:
www.workandincome.govt.nz/eligibility/seniors/superannuation/index.html.

	<ul style="list-style-type: none"> • For whānau and carers, the additional care required for a disabled member of the household can take away from their ability to work or limits their earnings. • Limited income and transport impacts on attending primary care and specialist appointments due to cost (Ministry of Health 2022a).
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The health system can learn from disabled people's experiences during COVID-19

The COVID-19 pandemic has revealed the inequities experienced by disabled people in having their health and wellbeing needs met by the health system (The Independent Monitoring Mechanism 2021). People receiving disability support services (DSS)¹⁴ were at greater risk of COVID-19 attributed hospitalisation and mortality than the rest of the population during 2022 (Ministry of Health 2022b; Whaikaha 2023b). Tāngata whaikaha Māori and disabled tāngata Tiriti reported not being listened to or understood by the health care sector regarding both their health care needs and their COVID-19, including long-COVID, symptoms (Baker and King 2022; Russell et al 2022). The prevalence of anxiety and/or depression were significantly higher among disabled people than non-disabled people and disabled people experienced disproportionate physical and social isolation (Donald Beasley Institute 2022; Paipa et al 2022). Public health information was not always delivered in accessible formats and disabled people reported more difficulties in accessing health and disability services when they needed them (Donald Beasley Institute 2022).

Disabled people were more likely than non-disabled people, across all modes of health care, to report at least one barrier to seeing a general practitioner (GP), barriers to getting a COVID-19 test and to report that COVID-19-related lockdowns affected their access to health care services (Health Quality & Safety Commission 2021; Russell et al 2022). This included higher likelihood of experiencing cancelled hospital appointments, inability to access their GP as usual, avoiding emergency departments when they usually would have attended, and difficulties in obtaining medicine from pharmacies. These insights demonstrate the failures of the health system in meeting the health and wellbeing needs of disabled people and their whānau, and a lack of partnership between the health system and the disability community.

During COVID-19, disabled people were more likely than non-disabled people to use telehealth options (Health Quality & Safety Commission 2021). Some disabled people noted the provision of telehealth services improved their access to health care by removing the need for travel, reducing travel times, and reducing unnecessary contact with other people

¹⁴ Whaikaha – Ministry of Disabled People (Whaikaha) funded disability support services are available to people who have a physical, intellectual or sensory disability (or a combination of these) which is likely to continue for at least six months and needs ongoing support to live independently, to the extent that ongoing support is required. These services are mainly for people under the age of 65 years. Whaikaha will also fund DSS for people with some neurological conditions that result in permanent disabilities, some developmental disabilities in children and young people, such as Autism, and physical, intellectual or sensory disability that co-exists with a health condition and/or injury (Whaikaha 2023a).

who may be unwell. Other disabled people voiced that telehealth led to increased difficulties in communicating with their GP. This highlights that needs, including accessibility needs, differ across the diverse disabled population and health care services therefore need to be tailored accordingly.

COVID-19 has also highlighted the strengths of disabled people and their whānau and disability communities and organisations in advocating for and meeting their own health and wellbeing needs, especially when the health system failed to do so (Russell et al 2022).

Clear themes and insights have emerged about the current health system

We acknowledge the strength of disabled people and their whānau in navigating a health system that has not always enabled or supported them in the ways they have needed. It is with this acknowledgement that we approached disabled people and their whānau to better understand the current state of the health system. Clear themes emerged from this engagement as outlined below.

Disabled people want to be heard in the health system and in control of their own health

Disabled people were clear during engagement that they want the health system to support them in taking an active and independent role in meeting their health and wellbeing needs. The current system is not seen as respectful of disabled people and their mana, nor one that puts their rights and wellbeing at the heart of service provision. This is particularly the case for tāngata whaikaha Māori, as well as tagata sa'ilimalo, people with learning disabilities, people with intellectual disabilities, neurodivergent people, disabled people from rainbow communities, disabled women, and disabled children.

Some people voiced that the intersection of ableism with other forms of discrimination, including sexism, racism and transphobia, in the health system has impeded them from exercising self-determination over their own health care. This included tāngata whaikaha Māori, tagata sa'ilimalo, disabled women, disabled people from ethnic communities and disabled people from rainbow communities.

For tāngata whaikaha Māori, tagata sa'ilimalo and disabled people from ethnic communities in particular, being seen collectively within the context of their whānau is essential to both individual and overall whānau wellbeing. This means that whānau, including carers and supporters, must also be included and listened to by the health system. This is currently not the experience of many whānau, carers and supporters of disabled people.

Tāngata whaikaha Māori and their whānau want the health system to be more responsive to their needs and aspirations

Through engagement, we heard that tāngata whaikaha Māori do not feel that Te Tiriti principles are being upheld across all aspects of the health system and that this is directly impacting their health and wellbeing. A health system that upholds Te Tiriti principles would improve health outcomes not only for tāngata whaikaha Māori, but all disabled people. Engagement with the community reflected many of the experiences being shared by tāngata whaikaha Māori in the Waitangi Tribunal's Health Services and Outcomes Inquiry.

Tāngata whaikaha Māori have reported feeling uninvolved in the decision-making surrounding their own health care (Russell et al 2022). Without the system recognising their self-determination, tāngata whaikaha Māori voiced that they are not being empowered to lead their own health care and are not supported by models of care that consider all of their health and wellbeing needs.

Tāngata whaikaha Māori reported that the Te Tiriti principle of active protection is not apparent in preventative care, as it is not accessible or culturally safe. The current system lacks support for, or acknowledgement of, the wider whānau, including whānau hāpai, as active parts of disabled people's health care.

Disabled people and their whānau want better access to supportive, community-based primary and preventative care

Accessible, local and high-quality primary and preventative care was a clear priority for many disabled people and their whānau, with clear frustration evident about the current inaccessibility of primary care. This contributes to poor health outcomes and can lead to a power imbalance between practitioners and disabled patients.

Key barriers to accessing primary and preventative care included:

- not enough time in 15-minute slots for GP appointments for disabled people to communicate their health needs in their preferred communication style, and higher costs for those who need longer appointment slots
- limited opening hours and strict appointment times of primary health services, which can lead to delayed or foregone care
- inaccessible preventative services (for example, inaccessible breast cancer screening and bowel cancer screening programmes)
- challenges finding a GP and other primary care providers and high turnover of health care staff in rural areas, which can impede relationship building
- inaccessible physical spaces of health services

- limited provision of health information in accessible formats, including labels on medicines, and information on the availability and importance of publicly funded screening services. This also impacts on privacy and undermines informed consent
- the high cost of oral health services and allied health services
- inconsistent access to preventative care and disability supports during key life stage transitions, such as from childhood to adulthood, and from adulthood to older age.

Disabled people and their whānau want a health system that facilitates access to wider services and supports to address broader drivers of poor health and wellbeing

Disabled people were consistent in their messaging that the health system was a key gateway to accessing other government supports. Disabled people and their whānau voiced that accessing timely and affordable diagnoses would assist in improving their broader wellbeing.

There were repeated calls for clearer pathways to accessing specialist diagnoses, including for rare conditions, and for adults accessing diagnoses for conditions normally diagnosed during childhood. Waiting for a diagnosis can delay access to other support services, which is detrimental to overall health and wellbeing. This is particularly the case when a health care diagnosis can strengthen an application for funding for support in a non-health related area.

Those whose impairments are not always recognised as disabilities in criteria for support services, including those with global learning delay, Fetal Alcohol Spectrum Disorder (FASD) and myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS), voiced that service access was too focused on diagnostic criteria rather than need.

Along with the different diagnostic criteria, people have struggled with constant reassessments for services in a health system (and wider social support system) that is exceedingly difficult to navigate. People felt that they constantly had to prove their disability, constantly had to repeat information and frequently felt disbelieved, which negatively impacted their physical and mental wellbeing.

Disabled people want to see themselves represented in a health workforce that is better equipped to meet their health and wellbeing needs

Engagement highlighted the importance of a health workforce that has sufficient skills and capacity to meet the needs of disabled people and their whānau. A strong theme was the lack of recognition and support by the health system of the skills and roles of the carer and support workforce in meeting the needs of disabled people. Carers and support workers must be valued, supported, resourced and trained to assist disabled people and their whānau to safely move through the health system.

Disabled people and their whānau also state that the health workforce has limited understanding of and reflective practice around ableism, racism and other forms of discrimination. This echoes the findings from the Health Quality and Safety Commission (2021), which showed that disabled people are less likely to report that doctors, nurses and other health care professionals treated them with kindness, understanding or respect, and are less likely to trust their doctors, nurses and other health care professionals.

This is in part due to a lack of disabled representation in the workforce, and a lack of disability rights-based and Te Tiriti-based training programmes within health qualification tertiary providers. This limits the cultural safety of health services for disabled people and their whānau.

Disabled people want to be visible in the health system

Disabled people and their whānau reported that the lack of data on the disabled population in Aotearoa New Zealand limits their visibility in the health system. They voiced that robust data would enable the health system to tailor support to meet their specific needs. This lack of data has particularly negative effects for tāngata whaikaha Māori: in December 2021, the Waitangi Tribunal found that the Crown was in active breach of the equity and active protection principles of Te Tiriti o Waitangi for not holding sufficient data on tāngata whaikaha Māori.

Disability organisations noted that there is no system-wide framework to identify disabled people by the National Health Index (NHI) or any other digital identifier to get a more accurate assessment of the prevalence of disability in the population. They noted that there was also a lack of disaggregated data by ethnicity, geographical location and nature of impairment, which limits the health system's understanding of the compounding effects of disability with other identity markers.

What are the medium and long-term trends?

Aotearoa New Zealand has an ageing population. As ageing is associated with higher rates of disability, it is expected that the disabled population will continue to grow (Ministry of Health 2021). This will disproportionately affect Māori and Pacific populations, who have the greatest growing proportion of older people (see the Hauora Māori Strategy and Te Mana Ola – The Pacific Health Strategy for more detail) (Ministry of Health 2020; Statistics New Zealand 2018; Statistics New Zealand 2020). The existing disabled population is likely to live longer than in previous generations, and existing impairments and conditions are often exacerbated with age. This will result in increased demand for specialised support as disabled people age.

The changing nature of our population profile is likely to create pressure across the health system, including through increased prevalence of some types of impairments that become more common with age (Health and Disability System Review 2020). To meet the needs of

the growing disabled population in Aotearoa New Zealand, there will likely be increased demand for a culturally competent health workforce that has capacity and capability to provide culturally safe health services. This workforce will need to understand the needs of disabled people, including impairment-specific and culturally specific needs.

In addition to the direct effects on individuals with impairments, the ageing nature of our population is likely to put more pressure on families and whānau, particularly intergenerational families and whānau with multiple people with impairments. Age will also lead to more people living alone, with associated impacts on health outcomes from loneliness and income disparity.

The disabling impacts of long-COVID are projected to grow. Evidence finds that long-COVID can be a physical or cognitive impairment (Morrow et al 2021; Maddux et al 2022; Ministry of Health 2022c; Stephenson et al 2022; U.S. Department of Health and Human Services 2021), and an increasing number of people identify as disabled due to their disabling experience of long-COVID (Russell et al 2022; Tak 2023). Long-COVID is seen in all age groups, but the risk of it being identified increases for those who are older and have multiple underlying chronic medical conditions (Ministry of Health 2021). While data is still emerging, it is likely that Māori will be disproportionately affected (Russell et al 2022). Māori continue to experience inequities in vaccination rates and incidence of severe illness requiring hospitalisation (Ministry of Health 2022d), both of which are associated with a higher likelihood of developing long-COVID.

Emerging research shows that there is a rising number of people who need high levels of support because of degenerative cognitive impairments, such as dementia. There is also increasing awareness of the prevalence of neurodevelopmental conditions such as attention deficit hyperactive disorder (ADHD), autism spectrum disorder (ASD), traumatic brain injury and FASD, especially in children (Saraf and Marks 2019; Cure Kids 2023). This includes increased recognition of different presentations of neurodiversity, including ADHD and ASD, in women (Mental Health Foundation 2022a; Mental Health Foundation 2022b). Increased prevalence and awareness of these conditions will likely result in increasing demand for health services.

The current state of health and wellbeing for disabled people shows that the health system must do more to meet their needs

As shown from previous research, engagement across the strategies, and broader health data, there are gaps in the health system's ability to meet the health and wellbeing needs of disabled people in Aotearoa New Zealand.

To address these gaps:

- the self-determination of disabled people and their whānau must be at the centre of the health system
- the health system must be accessible for disabled people and their whānau, and disabled people must be involved in system and service design
- the health workforce must be inclusive of disabled people, and must be culturally safe and responsive to their rights and needs
- the health system must be a stronger enabler for disabled people and their whānau to access support from other agencies to address their broader health and wellbeing needs
- there must be a robust health system data and evidence base that identifies the diverse disabled population and their health and wellbeing needs, including rare and complex needs, and tailors support accordingly.

The role of the Health of Disabled People Strategy is to guide health entities to work to improve the health and wellbeing of disabled people by filling these gaps. The next section outlines five priority areas for health entities to focus on to achieve pae ora | healthy futures for disabled people and their whānau, including consideration of what needs to change in the current health system.

Part 3: Priority areas for action

Five priority areas over the next ten years have been identified from analysis of research and engagement with disabled people. These priority areas will drive improvements in health and wellbeing outcomes for disabled people and their whānau:

- **Priority 1:** Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.
- **Priority 2:** Ensure the health system is designed by and accessible for disabled people and their whānau, and provides models of care that suit their needs.
- **Priority 3:** Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.
- **Priority 4:** Build health workforce capacity and capability to meet the needs of disabled people and their whānau.
- **Priority 5:** Increase the visibility of disabled people in health data, research and evidence, as part of an active learning system.

In this section, we describe the key priority areas where we need to see change. The priority areas are interdependent, and outline where action is most needed to continue shifting the health system towards achieving pae ora | healthy futures for disabled people and their whānau.

Provisional Health of Disabled People Strategy – Priority Areas

<p>Priority 1: Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.</p>	<p>Priority 2: Ensure the health system is designed by and accessible for disabled people and their whānau, and provides models of care that suit their needs.</p>	<p>Priority 3: Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.</p>	<p>Priority 4: Build health workforce capacity and capability to meet the needs of disabled people and their whānau.</p>	<p>Priority 5: Increase the visibility of disabled people in health data, research and evidence, as part of an active learning system.</p>
<ul style="list-style-type: none"> The health system will enable disabled people to exercise self-determination over their health and wellbeing Disabled people, including disabled children, and their whānau will be confident that their agency, autonomy, rights, will and preferences will be respected when engaging with the health system The health system will enable disabled people and chosen whānau, carers and supporters to exercise supported decision-making where appropriate Accessible health information will be provided and communicated clearly and appropriately throughout the entire health system The health system will prioritise prevention approaches, public health promotion and good health and wellbeing all along the life course 	<ul style="list-style-type: none"> Health entities will meaningfully partner with disabled people and their whānau to design fully accessible and community based primary and preventative care services Health services for both disability needs and other health needs will be of high quality, responsive and flexible in meeting the specific access needs of disabled people and their whānau Health entities will embrace the opportunities offered by technology to improve access to health information, health services and improved health outcomes for disabled people and their whānau Care pathways will be clear and streamlined to ensure continued care for disabled people across the life span and during key transition periods 	<ul style="list-style-type: none"> The health system will meet the needs of disabled people and their whānau by considering all of the factors that influence their health and wellbeing collectively The health system will support disabled people and their whānau to access the right support at the right time, to meet broader and intersecting health and wellbeing needs The health system will work closely with other agencies to ensure it is part of a coherent cross-government system that facilitates easy, timely and seamless access to information and services that address the broader health and wellbeing needs of disabled people and their whānau 	<ul style="list-style-type: none"> The health system will build health workforce capacity through recognising, valuing and enabling the development of diverse sets of skills and capabilities required There will be increased representation of the disability community, in its diverse breadth and including tāngata whaikaha Māori at every level of the health system, including in senior leadership positions The health workforce will be a culturally safe environment for all disabled people, particularly tāngata whaikaha Māori The health workforce will have improved understandings and application of Te Tiriti and Enabling Good Lives principles as they apply to the health of disabled people The wellbeing of the health workforce will be supported by the health system 	<ul style="list-style-type: none"> Disabled people and their whānau will have authority over how their data is used within the health system and how services are designed There will be a specific focus on improved data collection for those who experience the greatest inequities within the disabled population, including tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled ethnic communities and disabled rainbow communities Disabled people and their whānau will play a leading role in planning, designing, implementing, monitoring and evaluating health services to best meet their own health needs Health entities will report back to disabled people and their whānau regularly on how their insights are being leveraged to effect meaningful change

Priority 1: Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system

What we heard from disabled people and their whānau

Tāngata whaikaha Māori want *"a system that listens to our insights and [is] shaped by us"* – Ngā Wānanga Pae Ora 2023 participant.

"Don't question my authority to make the best decisions for me" – Ngā Wānanga Pae Ora 2023 participant.

Tāngata whaikaha Māori need *"Mana motuhake. More voices in positions of leadership/boards that are tāngata whaikaha"* – Ngā Wānanga Pae Ora 2023 participant.

"[Tāngata] Whaikaha need the support of the people they choose" – Ngā Wānanga Pae Ora 2023 participant.

Pae ora | healthy futures looks like *"Having medical professionals understand and listen to people with invisible disabilities"* – Health of Disabled People Strategy engagement participant.

Having needs met at a health care appointment would involve *"Having [health care] professionals listen to me and not my support person... Having all the [health care] professionals take the time to listen to me properly to understand what my needs are"* – Health of Disabled People Strategy engagement participant.

"The new system must require all NZ health providers, hospitals, doctors, pharma[cists], vaccine centres, therapists, psychiatrists, etc etc etc to provide all health related information that is available to any other person, in the requested accessible format, including but not limited to: Braille (contracted, [non-contracted], and digital file), Large print, digital text (screenreader accessible), audio, easy read, and NZSL. They must also accept information from the patient in all of these formats" – Tātou user.

Why this is a priority

A person's decision-making and agency over their health needs is critical to their health and wellbeing, and necessary for their rights to be realised.

We have heard from disabled people that they do not feel listened to within the health system and are sometimes not given the opportunity to voice their health needs. This was particularly voiced by people with communication impairments, people who use interpreters, disabled young people and people with intellectual and learning disabilities, who reported that practitioners often interacted with their supporters rather than directly with them. We

also know that the voices of disabled children and young people, especially those in state care, are not often heard by government.

The health system must recognise that disabled people and their whānau are experts in their own lives and enable them to exercise self-determination and authority over their health and wellbeing. This includes enabling disabled people to choose their support network, and still be heard alongside their supporters when exercising supported decision-making over their health and wellbeing needs.

Whānau, parents and carers have told us that they often feel ignored and dismissed by health practitioners when advocating for their disabled whānau member's needs. The health system must listen to and enable the expertise of whānau, carers and supporters in supporting disabled people to exercise their self-determination, including through supported decision-making and safeguarding responses where appropriate.

The concept of 'disability' has no equivalent within te ao Māori and most Māori with disability identify as Māori first. The Crown must meet its Te Tiriti obligations and partner with tāngata whaikaha Māori to enable them to fully exercise self-determination over their health and wellbeing, and have options and choice over how to best meet their health needs.

Enabling self-determination in the health system for disabled people and their whānau in their personal care also requires knowledge and leadership of disabled people and their whānau at all levels of the health system. The voices of disabled people and their whānau must drive health service design, delivery, monitoring and improvement.

What it will look like in the future

Disabled people and their whānau will be recognised as experts in their own lives and the health system will enable them to exercise self-determination over their health and wellbeing. Disabled people and their whānau will be confident that their agency, autonomy, rights, will and preferences will be respected when engaging with the health system.

Disabled children and young people will have their voices heard, and their rights respected, including tamariki and rangatahi Māori, Pacific youth, rainbow youth, and children and young people in state care. Health entities will recognise the maturity of young disabled people.

The health system will enable disabled people, whānau, carers and supporters to exercise supported decision-making where appropriate, and disabled people will feel confident that advanced care planning and advanced directives will be followed by health care practitioners.

Accessible health information will be provided and communicated clearly and appropriately throughout the entire health system. For example, labels on medication and accompanying information will be in braille for patients who choose braille as their preferred communication method, to enable disabled people to exercise their self-determination.

Health entities and services will regularly and meaningfully engage with disabled people and their whānau across the country, including in rural areas, to ensure disabled people and their

whānau can influence health system decision-making. The health system will listen to the lived experience of disabled people and their whānau and partner with them to respond to their needs and aspirations.

The health system will be guided by the voice of tāngata whaikaha Māori to ensure systems, processes and services reaffirm self-determination for tāngata whaikaha Māori.

The health system will prioritise prevention approaches, public health promotion and good health and wellbeing all along the life course. This includes early diagnosis and intervention to ensure that disabled people and their whānau have the appropriate information and support available to them from an early age, to enable them to exercise bodily autonomy and self-determination over their health and wellbeing.

It also includes prioritising initiatives that promote 'healthy ageing'. These initiatives aim to maintain quality of life for disabled older people to support them to do things that are important to them, enhance their participation and social connection, provide appropriate care, and assure dignity in their later years.

What needs to change

Health entities need to:

- Ensure the health system is re-oriented to be culturally safe for disabled people and their whānau to voice their health and wellbeing needs. This includes for tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled people from ethnic communities, disabled people from rainbow communities and the Deaf community, to ensure they can fully exercise self-determination over their health and wellbeing throughout their life.
- Ensure health entities enable, incentivise and value regular, meaningful engagement and ongoing, reciprocal relationships with disabled people and their whānau, particularly tāngata whaikaha Māori, including in rural areas.
- Ensure disabled people and their whānau are empowered and supported to participate equitably in decision-making through systemic provision of accessible communication methods and information in all health services and decision-making bodies.
- Ensure that disabled people have choice over the people who provide them with decision-making support, whether that be whānau, carers or other supporters.
- Ensure that whānau, carers and supporters, who are chosen by disabled people as their support network, are equipped to provide decision-making support.
- Improve access to interpreters for disabled people and their whānau, including New Zealand Sign Language interpreters, in all health care settings.
- Ensure that the Safeguarding Framework and Safeguarding Adults From Abuse (SAFA) response is embedded across all health settings.

- Support disabled people to exercise decision-making over their own health and wellbeing. This includes through tailored support for tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled people from rainbow communities, disabled people from ethnic communities, young disabled people, and older disabled people to exercise decision-making over their own health and wellbeing.

Links to other Pae Ora Strategies:

The themes in this priority area link to the following sections in the other Pae Ora strategies:

- **New Zealand Health Strategy:** Priority 1 – Voice at the heart of the system
- **Hauora Māori Strategy:** Priority 1 – Enabling whānau, hapū, iwi and Māori community leadership, decision-making and governance all levels
- **Te Mana Ola – The Pacific Health Strategy:**
 - Priority 2 – Te pāroru`anga, te apii`anga, e te akateretere`anga (disease prevention, health promotion and management of illness)
 - Priority 3 – Soalaupule (Autonomy and determination)
- **Women's Health Strategy:** Priority 1 – A health system that works for women
- **Rural Health Strategy:** Priority 1 – Decisions consider rural communities as a priority group

Priority 2: Ensure the health system is designed by and accessible for disabled people and their whānau, and provides models of care that suit their needs

What we heard from disabled people and their whānau

"[Tāngata whaikaha Māori need] access to kaupapa Māori services underpinned by Māori worldviews/principles" – Ngā Wānanga Pae Ora 2023 participant.

"A lot of the poor outcomes experienced by disabled people are through lack of access... to treatment, ... to information..." – Health of Disabled People Strategy engagement participant.

"I would... like to see one directory where people with disabilities can look up the type of service they need and find a provider or process easily - for example, where do I go if my equipment needs to be upgraded or repaired? What follow-up/treatment needs to be initiated by my GP, and where can I self-refer?" – Tātou user.

"Once our children become young adults services seem to be non exist[ent]" – Health of Disabled People Strategy engagement participant.

Why this is a priority

Disabled people and their whānau are finding the health system inaccessible, contributing to poor health and wellbeing outcomes. Here, the health system can be disabling itself for disabled people and their whānau, as its inaccessibility can create barriers to achieving pae ora | healthy futures for disabled people. For example, the inaccessibility of equipment in health services can prevent disabled people from having their health needs addressed in a timely and effective way.

Disabled people and their whānau have told us that they want more accessible, flexible, integrated, community-based and culturally safe health care, focused on preventative care. This includes person and whānau-centred models of care that consider disabled people's physical, mental and emotional health in the context of their broader whānau, community and environment.

For tāngata whaikaha Māori, an understanding of health and pae ora includes mauri ora, whānau ora and wai ora. Tagata sa'ilimalo and ethnic communities have similarly voiced the need for the health system to acknowledge Pacific and ethnic community-specific collectivist approaches to understanding health and wellbeing.

Integration of health services and systems is needed so that disabled people and their whānau have seamless access to, and choice of, timely, affordable, high quality, high

performing and culturally safe services that meet their needs throughout the life span. This includes during key transition periods, for example, when disabled people are leaving prison and reintegrating into the community, to ensure that people do not fall through the gaps.

What it will look like in the future

Disabled people and their whānau will play an active and leading role in determining the design and delivery of health services across the whole health system. Health entities will meaningfully partner with disabled people and their whānau to plan design, commission, deliver, monitor, evaluate and deliver fully accessible and community-based health services, particularly in primary and preventative care, according to their needs.

Health services for both disability needs and other health needs will be of high quality, responsive and flexible in meeting the specific access needs of disabled people and their whānau. Services that are designed and delivered by disabled people and their whānau will make the health system an attractive place to work for disabled people and will support the broader health workforce to deliver high quality and responsive care tailored to meet disabled people's needs.

Health entities will support disabled people and their whānau, including disability organisations, to deliver their own accessible and local services to their communities. The health system will recognise the value of kaupapa Māori services and mātauranga Māori, including rongoā Māori, in meeting the health needs of tāngata whaikaha Māori, as well as ensuring that accessibility for tāngata whaikaha Māori is enabled in mainstream services.

Health services will be provided in locations and settings that are accessible to disabled people and their whānau, to keep people well in their communities. This will include support for older people with disabilities to remain in their homes and with their whānau for longer, and the provision of screening services closer to home for disabled people in rural areas. Localities will lead the work on identifying and addressing the health needs of their disabled populations.

Health entities will ensure that disabled people receive equitable access to high quality health care, including care unrelated to disability. For example, disabled people and their whānau will have equitable access to high quality sexual and reproductive health care services, and to health care that appropriately and safely responds to their experiences of violence and abuse. The same level of preventative care will be available to disabled people as non-disabled people, particularly cancer screening services.

Health entities will embrace the opportunities offered by technology to improve access to health information, health services and models of care that best suit the needs of disabled people and their whānau. This may include leveraging the potential opportunities, where appropriate and in partnership with disabled people and their whānau, provided by precision health, including the use of artificial intelligence and machine learning, to help personalise

health care in a targeted way (Ministry of Health 2023b).¹⁵ Health entities will take into consideration the gaps in digital literacy within the disabled population, and will ensure that any leveraged technological opportunities will not leave behind those with lower levels of digital literacy. Health entities will also work in partnership with disabled people and their whānau to ensure that the purpose and use of precision health meets ethical and moral obligations.

Care pathways will be clear, especially for people with complex and chronic conditions. Referrals and information-sharing will be seamless and timely between health services, including through innovative technology, to ensure continued care for disabled people and their whānau across the life span and during key transition periods.

Disabled people and their whānau will have increased access to multi-disciplinary health care teams to streamline care pathways, reduce unnecessary duplication of health services and ensure all their health needs are being met. Where needed, navigators will support disabled people and their whānau to make the right connections across health services.

Physical health service spaces will meet all accessibility needs to enable disabled people and their whānau to enter and move safely through their health service experience in a way that best meets their needs. This includes spaces that are inclusive and culturally safe physical environments for all disabled people, as well as Māori, Pacific peoples, rainbow communities, ethnic communities and the Deaf community.

What needs to change

Health entities need to:

- Ensure everything that affects disabled people and their whānau in the health system is guided by the voice of disabled people and their whānau. The diversity of the disability community must be heard, including those who have not always had their voices heard. This includes partnering with tāngata whaikaha Māori, whānau, hapū, iwi, Māori communities and providers to ensure the voices of tāngata whaikaha Māori are heard.
- Ensure disabled people and their whānau are enabled to lead the delivery of services in their communities. These services must be responsive to community needs and flexible to adapt as circumstances change.
- Partner with whānau, hapū, iwi and Māori communities and providers, including tāngata whaikaha Māori, to improve the capability and capacity of kaupapa Māori and whānau-centred service providers. This is to enhance the availability and accessibility of kaupapa Māori services and mātauranga Māori practices, and facilitate choice of services and health care models for tāngata whaikaha Māori.

¹⁵ This will require reviewing the legislative and regulatory framework, considering infrastructure and investment implications, and addressing ethical issues to ensure that new technologies are delivered safely and equitably. See the Manatū Hauora *Long-term Insights Briefing – Precision Health: Exploring opportunities and challenges to predict, prevent, diagnose and treat disease more precisely in Aotearoa New Zealand* for more detail.

- Partner with tagata sa'ilimalo and Pacific providers, rainbow providers, ethnic communities and the Deaf community to improve the availability and accessibility of culturally safe health services.
- Invest in identifying unmet need, early diagnosis and intervention, including for rare conditions and disabling mental health and chronic health conditions.
- Invest in research and initiatives that help all parts of the health system to harness innovation and new technologies to improve access to health information, health services and models of care that best meet the needs of disabled people and their whānau. This includes initiatives aimed at improving digital literacy within the disabled population, while recognising that digital means are not accessible to all disabled people.
- Ensure all health care spaces are accessible, including accessible waiting rooms and hospital emergency departments for those with sensory impairments and sensitivities.
- Systematically address known barriers to care for disabled people and their whānau, including cost of services, opening hours of services and fragmented referrals processes, particularly in rural areas.
- Invest in health care approaches that address as many aspects of disabled people's health care needs as possible in a person and whānau-centred way, including multidisciplinary team approaches to health care where applicable.
- Review the current use of navigators across the health system to identify and strengthen what is working well, and fill gaps in places where culturally safe navigators could improve connections for disabled people and their whānau, ensuring consistency across regions.

Links to other Pae Ora Strategies:

The themes in this priority area link to the following sections in the other Pae Ora strategies:

- **New Zealand Health Strategy:** Priority 2 – Flexible, appropriate care
- **Hauora Māori Strategy:** Priority 4 – Enabling culturally safe, whānau-centred and preventative primary health care
- **Te Mana Ola – The Pacific Health Strategy:** Priority 4 – Haitiaaga moui malolo (Access)
- **Women's Health Strategy:**
 - Priority 2 – Improving health care for issues specific to women
 - Priority 3 – Better outcomes for mothers, whānau and future generations
- **Rural Health Strategy:**
 - Priority 2 – Prevention: Paving the path to a healthier future
 - Priority 3 – Services are available closer to home for rural communities
 - Priority 4 – Rural communities are supported to access services at a distance

Priority 3: Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing

What we heard from disabled people and their whānau

"[Being healthy means] Living a full life surrounded by whānau doing things that matter" – Ngā Wānanga Pae Ora 2023 participant.

"It shouldn't leave people with health issues having to cart around their entire notes and things like that, to make sure that they are getting the help that they need" – Health of Disabled People Strategy engagement participant.

"I don't even understand the difference between the health system and the education system and I felt really pinged around for a long time... if we had issues around things like ramps it was very difficult... I just used to feel that health would say that's education and education would say that's health. I just felt so drowning in the middle" – Health of Disabled People Strategy engagement participant.

"Most of my work is juggling the different agencies we have in our community" – Health of Disabled People Strategy engagement participant.

Why this is a priority

Health and wellbeing extend beyond the health system and include broader determinants of health, such as housing, education and income. An approach that considers all factors that influence health and wellbeing, like those of te ao Māori and Pacific worldviews, is essential to achieve pae ora | healthy futures for disabled people and their whānau.

Wai ora acknowledges the importance of Māori connections to whenua as part of the environments in which Māori live and belong – and the significant impact this has on the health and wellbeing of individuals, whānau, hapū, iwi and Māori communities. An environment that is compatible with good health reflects the need for Māori, including tāngata whaikaha Māori, to have access to resources (such as good quality housing, safe drinking water, clean air, healthy food) and to live in environments that support and sustain a strong, flourishing mauri and a healthy and empowered whānau.

There is a range of broader determinants that particularly impact the health and wellbeing of disabled people and their whānau (see Part Two: Where are we now?). Key determinants include good quality, safe and accessible housing, income, suitable employment, and supportive and accessible education. The distribution of these determinants inequitably

impacts Māori, including tāngata whaikaha Māori (see the Hauora Māori Strategy for more detail). To improve the health and wellbeing of and achieve pae ora | healthy futures for disabled people and their whānau, health entities must work closely with other agencies.

According to the New Zealand Productivity Commission, a barrier to addressing persistent disadvantage is the 'fragmented and siloed nature of government' (New Zealand Productivity Commission 2022). The health system should be an enabler for disabled people and their whānau to access support from other agencies that will address their broader health and wellbeing needs. We have heard that receiving a health condition or disability diagnosis from the health system can assist disabled people and their whānau to access support from other agencies, as this diagnosis serves as a 'validation' of their need for support. Delays in receiving diagnoses from the health system can therefore result in delays to accessing these other forms of support. For example, we have heard that delays in receiving a health system-based specialist assessment and diagnosis for ASD, ADHD and FASD has led to delays in accessing support in education settings.

What it will look like in the future

The health system will meet the needs of disabled people and their whānau by considering all the factors that influence their health and wellbeing collectively. This means the health system will recognise and consider the intersectional nature of people's identities and lived experiences, and the impact this has on their overall health and wellbeing. This includes recognition that disabled people have different experiences and health and wellbeing needs based on gender, ethnicity, sexuality, geographic location and other aspects of their identity.

The health system will support disabled people and their whānau to access the right support at the right time, to meet their broader and intersecting health and wellbeing needs. This means the health system will work closely with other agencies to ensure it is part of a coherent cross-government system that facilitates easy, timely and seamless access to information and services that address broader health and wellbeing needs. Health services will be better connected to social services, including housing and education services, to prevent disabled people and their whānau from having to unnecessarily repeat their stories and concerns multiple times, and to prevent delays in accessing support.

Where health is not the lead sector for some areas of work (for example, housing and income), health entities will take an active role in advocating for, supporting and partnering with other agencies, organisations and communities to deliver information and services that meet the broader health and wellbeing needs of disabled people and their whānau.

This will include working in partnership with other sectors to improve health and wellbeing outcomes for tāngata whaikaha Māori, and to respond to the needs, aspirations and priorities identified by tāngata whaikaha Māori, whānau, iwi-Māori partnership boards and local leadership.

What needs to change

Health entities need to:

- Assess current interaction points between health and wider government services, and leverage cross-agency partnerships (at both central and local levels) to improve connections between these services, including housing, education, employment, justice, corrections and child and youth wellbeing services.
- Strengthen partnerships with tāngata whaikaha Māori and Māori providers to deliver kaupapa Māori and other mātauranga Māori services that consider all the factors that influence the health and wellbeing of tāngata whaikaha Māori.
- Strengthen partnerships with non-government organisations, communities and disabled people and their whānau to deliver community-based supports and services for disabled people and their whānau that consider all the factors that influence their health and wellbeing. This includes improved partnership with:
 - tagata sa'ilimalo and Pacific providers, to deliver by-Pacific, for-Pacific services
 - other community organisations, such as rainbow organisations and ethnic community organisations.
- Continue to support the Social Sector Commissioning 2022-2028 Action Plan, with an explicit focus on social sector commissioning to address the broader determinants of health and wellbeing for disabled people and their whānau.
- Ensure there is effective navigation in the health system to help disabled people and their whānau to access the appropriate supports to meet their broader health and wellbeing needs.

Links to other Pae Ora Strategies:

The themes in this priority area link to the following sections in the other Pae Ora strategies:

- **New Zealand Health Strategy:**
 - Priority 5 – A resilient and sustainable system
 - Priority 6 - Partnerships for health and wellbeing
- **Hauora Māori Strategy:** Priority 2 – Strengthening whole-of-government commitment to Māori health
- **Te Mana Ola – The Pacific Health Strategy:** Priority 1 – Vaqaqacotaka na yavutu ni tiko bulabula (Population health)
- **Women's Health Strategy:** Priority 4 – Living well and ageing well
- **Rural Health Strategy:** Priority 1 – Decisions consider rural communities as a priority group

Priority 4: Build health workforce capacity and capability to meet the needs of disabled people and their whānau

What we heard from disabled people and their whānau

"[Tāngata whaikaha Māori need] cultural safety from all employers. Equal opportunity and progression for tāngata whaikaha in the workforce" – Ngā Wānanga Pae Ora 2023 participant.

"It's a person you're going to ... you don't know them. You see them probably once, I mean I see them quite a lot unfortunately, but I don't have a relationship with them. And you have 15 minutes with them, and less than 15 minutes, to get the things you need" – Health of Disabled People Strategy engagement participant.

"Require all those responsible for providing health services to have a basic knowledge of disabilities, accessibility, and disability rights, the Deaf community, and d/Deaf rights. And a knowledge of how to interact with and provide care that meets the basic requirements of disabled people and d/Deaf people" – Tātou user.

Why this is a priority

The health workforce needs to be better equipped to understand and act on the needs of the diverse disability community. This includes improved understanding of disability rights, disability-specific and impairment-specific needs, including communication needs, and culturally specific needs. This requires the health system to address the intersection of ableism, racism, transphobia, sexism and other forms of discrimination that can lead to disabled people feeling ignored when advocating for their health needs, not receiving the same quality of care as non-disabled people, and ultimately experiencing poorer health and wellbeing outcomes. This has particularly been voiced by tāngata whaikaha Māori, as well as tagata sa'ilimalo, older people, disabled women, disabled people from rainbow communities and disabled people from ethnic communities.

The health system must acknowledge the skills and capabilities required to support the needs of disabled people and their whānau, including tāngata whaikaha Māori, as well as tagata sa'ilimalo, and people with disabling complex and chronic conditions, such as FASD, ME or CFS, long-COVID and disabling mental health conditions.

Disabled people should be represented in all parts of the health workforce throughout the health system, particularly in senior leadership and decision-making positions. There should be opportunities for the health workforce to grow capability to better reflect and service the

needs of the disability community. This includes for tāngata whaikaha Māori, as well as tagata sa'ilimalo and people with intellectual and learning disabilities.

Greater support, including wellbeing support, is needed for the disabled and non-disabled health workforce. We have heard that the workforce is experiencing burnout, including unpaid and informal carers and supporters, who have limited access to respite to allow them to rest and prioritise their own wellbeing. This particularly affects the wellbeing of women, who disproportionately make up the paid and unpaid carer workforce (Carers New Zealand 2023)¹⁶, and carers who are reaching older age¹⁷ and/or develop physical and mental impairments themselves. It also affects the health, including mental health, and wellbeing of young people who are ongoing carers of disabled whānau members (Hanna and Chisnell 2019).¹⁸

What it will look like in the future

The New Zealand Health Strategy has set out that to protect, promote and improve the health of New Zealanders, achieve equity in health outcomes and build towards pae ora | healthy futures, we need:

- a workforce that is available to meet service and population needs
- a workforce that is equitably accessible to provide choice and timely care
- a responsive workforce that is culturally safe, representative of and flexible to population health needs
- a productive workforce that is motivated and empowered
- a quality workforce that delivers safe, effective and efficient care and partners with Māori.

What this looks like for the disabled health workforce and disabled people receiving care is described below.

The health system will build health workforce capacity through recognising, valuing and enabling the development of the diverse sets of skills and capabilities required to deliver equitable health outcomes for disabled people and their whānau. This includes valuing and enabling the skill development of unpaid carers, supporters, advocates and navigators who hold critical skills and capabilities to meet the health and wellbeing needs of disabled people. The disabled health workforce will also be enabled to develop the skills they want and need to acquire and work in ways that effectively meet community needs.

The health workforce will be well connected to disabled people and their whānau. This means that disabled people and their whānau will be able to access a diverse, multi-disciplinary workforce with appropriately qualified health professionals in locations that are

¹⁶ 63% of Aotearoa New Zealand's family carers are women. Unpaid carers are twice as likely to be female.

¹⁷ In 2019, approximately 16% of carers were aged 65 years or older (Office for Seniors 2019).

¹⁸ Approximately 5% of young people aged 12 to 18 years provide regular care to someone seriously affected by a disability or long-term illness (Malatest International et al 2022).

accessible to them. This will offer disabled people and their whānau choice when accessing the health workforce.

The health system will become a leading employer of disabled people in Aotearoa New Zealand. There will be increased representation of the disabled population, in its diverse breadth, at every level of the health system, including in senior leadership positions. This will include increased representation of tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled women, disabled people from rainbow communities and disabled people from ethnic communities. Health entities will recognise and address ableism in employment practices and adapt these practices to meet the needs of disabled employees. Increased disability representation will ensure that health services are funded, designed and delivered by disabled people, who will have the skills and disability-specific and culturally specific understandings required to deliver accessible, community-based and better-quality care.

The health workforce will be a culturally safe environment for all disabled kaimahi and patients, particularly tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled women, the Deaf community, disabled people from ethnic communities and disabled people from rainbow communities.

The health workforce, including mental health professionals, will have improved understandings and application of Te Tiriti and EGL principles as they apply to the health of disabled people, as well as improved understandings of disability rights, disability-specific and impairment-specific needs. This will include improved understandings of the needs of disabled older people, and of the sexual and reproductive health needs of disabled people, particularly disabled women and disabled people from rainbow communities, including gender affirming health care. The health workforce will be supported to understand the rights and needs of disabled people and their whānau through appropriate funding, training and other supports, including wellbeing support.

The wellbeing of the health workforce will be supported by the system to enable the workforce to improve health and wellbeing outcomes for disabled people and their whānau. Working in the health system will be more rewarding and empowering, with greater opportunities to move between careers. Employers, regulators, educators and service designers will collaborate to enable the workforce to work flexibly, empowering them to deliver care where and how disabled people and their whānau need. This means a stronger inter-professional culture and leadership, fairer working conditions and embedding the norms of flexible working.

The Māori health workforce, including tāngata whaikaha Māori, will be representative of the Māori population, and will have increased capacity and capability in both mainstream and kaupapa Māori health services.

What needs to change

Health entities need to:

- Ensure the health system values the breadth of skills and capabilities required to support the health and wellbeing needs of disabled people and their whānau.
- Partner with disabled people and their whānau, iwi and Māori, Pacific, rainbow and ethnic communities' disability organisations to understand the skills and capabilities required to meet the health and wellbeing needs of disabled people and their whānau and design health services accordingly. This will provide opportunities for the workforce to utilise their skills and deliver models of care that meets the health and wellbeing needs of disabled people and their whānau.
- Support the health workforce to build the skills, capabilities and competencies needed to meet the breadth of health and wellbeing needs of the diverse disabled population. This includes:
 - rights-based and cultural safety training to enable the workforce to identify their biases, and training to eliminate ableism, racism, sexism, transphobia and other forms of discrimination from the health system
 - training to develop workforce competencies regarding disabled people's sexual health and reproductive needs, and disabled people's experiences of violence and abuse
 - support to recognise the expertise and skills of disabled people's whānau, carers and supporters, including through specific training on informed consent and supported decision making.
- Support whānau, carers and supporters to upskill to better meet the health and wellbeing needs of disabled people, and to enter the formal health workforce if they choose. This includes through tailored training programmes.
- Remove barriers for disabled people to complete health care qualifications and enter the health workforce. This will better enable the disabled health workforce to build the careers they want and work safely and effectively within a team to support better health outcomes for other disabled people and their whānau. This will require changes to the way that the health system develops and recognises skills and capabilities and changes to the models of working that are funded or encouraged, as well as safe working environments and enabling workplace cultures.
- Remove barriers for Māori, including tāngata whaikaha Māori, to complete health care qualifications and enter the health workforce.
- Ensure there is a sustained commitment to recruiting and investing in a diverse disabled health workforce in all health entities, including tāngata whaikaha Māori and tagata sa'ilimalo workforces. This will require sustained commitment to designing services that work for disabled people, and creating employment conditions that are mana enhancing for and attractive to disabled people.

- Support the wellbeing of the disabled health workforce by providing accessible materials, workplaces and access to accessible accommodations on the job, including flexible employment models.
- Explore health system-funded respite options to provide wellbeing support for unpaid whānau, carers and supporters.
- Work alongside cross-agency partners and non-government organisations, in partnership with disabled people and their whānau, to support flexible working and childcare arrangements for carers and supporters of disabled people.

Links to other Pae Ora Strategies:

The themes in this priority area link to the following sections in the other Pae Ora strategies:

- **New Zealand Health Strategy:** Priority 3 – Valuing our workforce
- **Hauora Māori Strategy:** Priority 3 – Growing the Māori health workforce and sector to match community needs
- **Te Mana Ola – The Pacific Health Strategy:** Priority 5 – Kau ngāue (Workforce)
- **Women’s Health Strategy:** Priority 1 – A health system that works for women
- **Rural Health Strategy:** Priority 5 – A flexible and robust rural health workforce

Priority 5: Increase the visibility of disabled people in health data, research and evidence, as part of an active learning system

What we heard from disabled people and their whānau

"The Crown does not know who identifies as Tāngata Whaikaha Māori as no data is collected that allows us to self-identify as who we are. Nor for that matter have tāngata whaikaha Māori, whānau hauā, and Māori with lived experience of disability, as a group or population, had any meaningful opportunity to develop collective identity that might be measurable" – Dr Tristram R. Ingham, Testimony in Wai 2575 (Ingham 2023).

"Good quality data and research on disability are essential to provide the basis for policy and programs, resource allocation, and to better understand issues and solutions in providing health care for disabled people" – Submission to the Health of Disabled People Strategy.

"It is very difficult to establish prevalence rates for the abuse of disabled people because of the lack of systematic data collection" – Submission to the Health of Disabled People Strategy.

Why this is a priority

The health system has a responsibility to improve health outcomes for disabled people, which requires improved understanding of the size and demographics of the diverse disabled population. There is a lack of up-to-date, detailed data on the diverse disabled population in Aotearoa New Zealand. There is a particular absence of data on self-identified disability, data on communities within the broader disability population, and data that captures disability alongside other identity markers, such as ethnicity, gender and sexuality.

Improved data and research identifying the diverse disabled population makes their health outcomes and needs visible to the health system. This, in turn, enables the health system to monitor outcomes accurately and actively for disabled people, plan, target and fund services, research and workforce to meet their needs, and identify and address barriers contributing to differences in outcomes between disabled and non-disabled people. Robust data also enables accurate performance reporting, monitoring and evaluation of health entities in meeting the health and wellbeing needs of disabled people.

We have heard that monitoring system performance for Māori, particularly tāngata whaikaha Māori, and holding the system to account for upholding Te Tiriti requires further development. Effective monitoring requires quantitative and qualitative insights based in the voices of tāngata whaikaha Māori, whānau, hapū, iwi and Māori communities.

We must have unified, enduring data gathering systems that are accessible to disabled people and where privacy and security are paramount. This data will need robust governance and alignment with respect to Māori data sovereignty protocols.

Disabled people and their whānau have told us that greater accountability is needed across the health system. This is to ensure that people can advocate for themselves and their whānau without fear of losing access to services. They have also told us that the feedback loop between health agencies and the disability community needs to be improved, so that disabled people and their whānau can see where and how their insights are leading to change to improve their health and wellbeing outcomes.

What it will look like in the future

We will have health data for disabled people and their whānau, including tāngata whaikaha Māori, that is meaningful, up-to-date and used to continuously improve the health system's ability to meet disabled people's needs. Accurate health data for disabled people will be reported regularly and used to inform commissioning and service design decisions.

Disabled people and their whānau will have authority over how their data is used within the health system and how services are designed. The health system will ensure that disabled people, communities and organisations can determine the way that health data for disabled people is collected, reported, and interpreted for continuous quality improvement of health policies and services. Mechanisms to produce, manage, use and monitor data will include participation and leadership from, and respect for the rights of, disabled people, particularly tāngata whaikaha Māori. Health entities will regularly report about equity in health service provision and health outcomes for disabled people.

Disabled people and their whānau will have regular access to up-to-date, accurate and meaningful evidence and data relevant to their health and wellbeing needs. This includes access for tāngata whaikaha Māori to Māori health research and data. This evidence and data will be used for continuous quality health system improvement, to develop innovative solutions and to monitor progress in the health system.

There will be a specific focus on improved data collection for those who experience the greatest inequities within the disabled population. This includes tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled people from ethnic communities, disabled children and young people, including those in state care, disabled women, disabled people from rainbow communities, people with intellectual and learning disabilities and people who are neurodiverse.

Disabled people and their whānau will play a leading role in planning, designing, implementing, monitoring and evaluating health services to best meet their own health and wellbeing needs. Measures of hauora for tāngata whaikaha Māori will reflect what is most important to tāngata whaikaha Māori and will consider mātauranga Māori practices and cultural expressions. Health entities will report back to disabled people and their whānau regularly on how their insights are being leveraged to effect meaningful change.

What needs to change

Health entities need to:

- Partner with disabled people and their whānau to collect robust, meaningful, timely and accurate data to be able to determine the health and wellbeing needs of disabled people, and plan and monitor system performance. This includes commissioning and supporting the creation and maintenance of data frameworks and regular reporting on accurate disaggregated data, such as ethnic-specific disability data and data on communities within the disabled population, particularly tāngata whaikaha Māori. Disaggregated data that maps to health data, including for rare and multiple coexisting conditions, will increase opportunities for service improvement.
- Support disability community-led research on the health and wellbeing needs and aspirations of disabled people, and the interaction of disability with other identity markers. Priority populations for research include tāngata whaikaha Māori, self-identified disability, intellectually disabled people, neurodiverse people, people with disabling mental health conditions, people with chronic conditions, tagata sa'ilimalo, disabled people from rainbow communities, disabled people from ethnic communities, disabled women, and disabled children and young people, including those in state care.
- Support Māori-driven research on and evaluation of the health and wellbeing needs and aspirations of tāngata whaikaha Māori.
- Enable regular, meaningful engagement and ongoing, reciprocal relationships with disabled people and their whānau, particularly with tāngata whaikaha Māori. This must include structures to ensure consistent feedback loops, so that disabled people and their whānau can see where and how their insights are leading to change.
- Provide regular access to evidence and data for disabled people and their whānau.
- Provide appropriate monitoring and evaluation of equity of health care access, equitable quality of health care services and equity of health outcomes for disabled people and their whānau at all levels of the health system, including policy and service provision.
- Ensure all accountability and complaints mechanisms are timely, transparent, culturally safe, responsive and fully accessible to all disabled people and their whānau.
- Ensure that health entities act to address inequities found in data, research and evidence between disabled and non-disabled people and within the disabled population.

Links to other Pae Ora Strategies:

The themes in this priority area link to the following sections in the other Pae Ora strategies:

- **New Zealand Health Strategy:** Priority 4 – A learning culture
- **Hauora Māori Strategy:** Priority 5 – Ensuring accountability for system performance for Māori health
- **Te Mana Ola – The Pacific Health Strategy:** Priority 3 – Soalaupule (Autonomy and determination)
- **Women’s Health Strategy:** Priority 1 – A health system that works for women
- **Rural Health Strategy:** Priority 1 – Decisions consider rural communities as a priority group

DRAFT

PROACTIVELY RELEASED

Part 4: Delivering our commitment to change

Turning strategies into action

One of the objectives of the health system reforms is to better align and integrate the accountability arrangements that set direction and priorities for health agencies. The reforms put in place a new approach that aims to ensure clarity and coherence, from long-term strategic objectives to shorter-term priorities and expectations.

This new approach provides clear roles for key documents, underpinned by statutory requirements in the Pae Ora Act:

- Health strategies are intended to set a long-term (five to ten years) direction for improving health and identify priorities and opportunities for the health system. The strategies provide a vision and indicate the types of change necessary over the medium and long term. Strategies do not make commitments to particular actions or require health entities to undertake specific activities – instead they describe potential choices and issues to be considered, to inform the decisions that the Government will make on what actions are taken forward, and when. Health entities must take the strategies into account in carrying out their responsibilities.
- The Government Policy Statement (GPS) sets out the specific priorities and expectations for the health system over a three-year period. It is the key document for Government to set its priorities, confirm actions for entities and funding for the health system, and detail how success will be measured. The GPS will reflect the long-term direction of the strategies, and include more detailed actions for health entities in the short-term that work towards the strategy aims. The GPS is agreed by Ministers, and health entities must give effect to it.
- The New Zealand Health Plan (NZHP) is a three-year national service plan, that specifies the service priorities and areas for improvement that will achieve the Government's expectations in the GPS. The NZHP includes more detailed plans for health services, programmes and enablers that show how the health entities will meet priorities within the funding available. The NZHP is developed by health entities and approved by Ministers.

These documents work together to set a consistent direction for the health system, which is then developed into more specific actions and costed service plans that span a multi-year period, as illustrated in Figure 1 below.

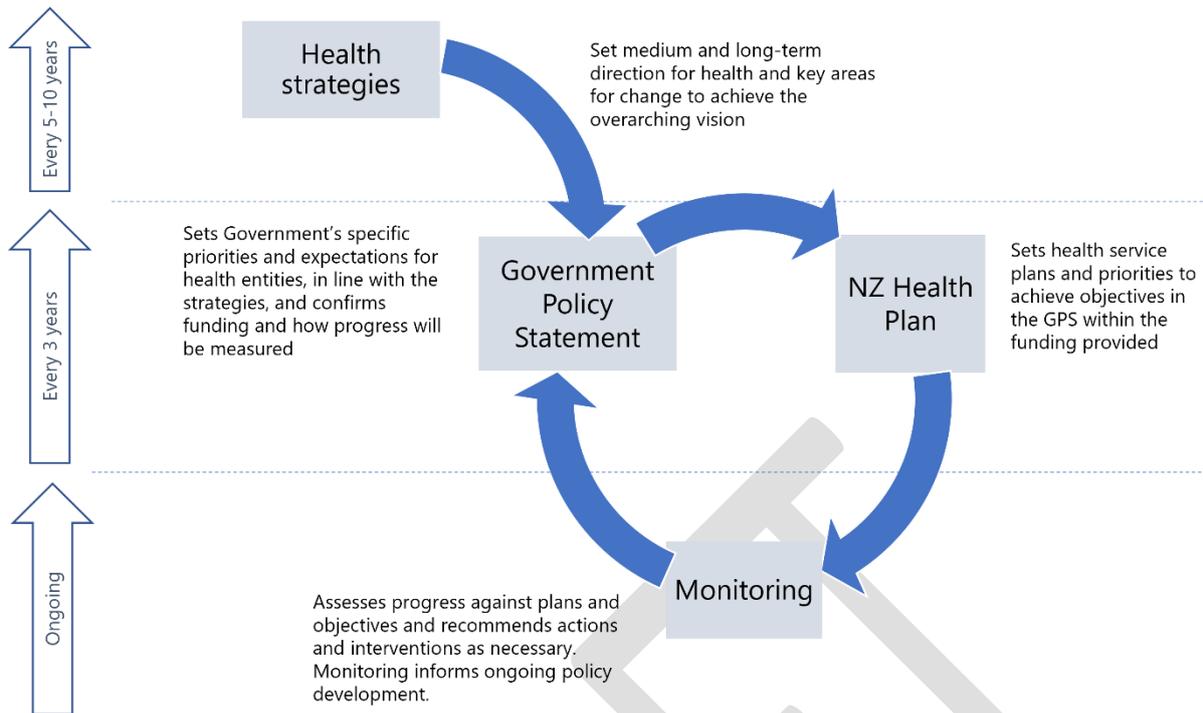


Figure 1: Turning Strategies into Action

This new approach provides a clear pathway for translating strategies into action, and monitoring the impact of strategies and the performance of agencies. The role of health strategies is critical to providing the long-term vision and priority areas that inform decisions in the other documents.

As the Government determines the first three-year GPS for 2024-2027, and in subsequent cycles, the strategies will be turned into clear expectations and actions that will provide the opportunity to achieve the changes set out.

Monitoring outcomes

The health strategies set a direction towards achieving pae ora | healthy futures for all New Zealanders, and include goals to eliminate health inequities and improve outcomes. Monitoring progress towards this vision requires a long-term approach to measuring key health outcomes.

The GPS will set requirements for measures and indicators that will be used to monitor and assess the progress of the health system, and of individual entities, in achieving these goals. These measures will combine more enduring and long-term outcomes that are intricately linked to the strategies, as well as more specific measures that reflect three-year priorities and help drive action in certain areas. They will support Manatū Hauora, in its stewardship role, to track delivery of the strategies and report on impacts over time.

Ensuring high-quality data will be essential to monitoring outcomes. This is particularly the case for monitoring inequities between population groups, which require a breakdown of data to make comparisons and develop insights.

PROACTIVELY RELEASED

The current health data sets contain numerous gaps, both for disabled people and their whānau and services (eg, primary and community care), that will need to be addressed through purposeful, targeted data and analytics plans to ensure that the intended impact of the strategies can be appropriately monitored for all groups (see Priority 5 for more detail).

Ongoing evaluation

In addition to monitoring the intended outcomes of the strategies to account for the success of their delivery, it is also important to ensure ongoing evaluation of the strategy direction itself to assure that it remains appropriate.

Over the coming years as the strategies are developed into firm actions in the GPS and NZHP and then implemented, it will be necessary to invest in ongoing research and evaluation to continue to build our understanding of the direction and evolve it where needed. This may include:

- evaluating the impact of the Pae Ora Act, the effectiveness of its implementation and lessons for the system structure
- evaluating the new accountability approach, the roles of strategies, the GPS and NZHP, and the effectiveness of their delivery and alignment in achieving system goals
- evaluating the process undertaken to develop the health strategies, to draw insights on the benefits of different engagement approaches, analysis and development.

These areas for evaluation will be developed further to support a refreshed approach to research across the health system.

Finalised Health of Disabled People Strategy

After publication of this provisional strategy, further targeted engagement will occur with the disability community. This will allow for further shaping of the identified priority areas. A finalised Health of Disabled People Strategy is expected to be published after the targeted engagement process.

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Appendix One: Definition of pae ora for Māori

Pae ora is a holistic concept that includes three interconnected elements: whānau ora, mauri ora and wai ora. Pae ora provides a platform for Māori to live with good health and wellbeing in an environment that supports Māori to flourish and thrive as Māori.

The concept encourages everyone in the health and disability system, as contributors to Māori wellbeing, to work collaboratively, to think beyond narrow definitions of health and to provide high-quality and effective health services. Pae ora affirms holistic Māori approaches – strongly supporting Māori-led solutions and Māori models of health and wellness. Pae ora recognises the desire for Māori to have control over their future health and wellbeing.

Whānau ora	Whānau ora is a fundamental philosophy for creating strong, healthy and empowered whānau. A strong, healthy and empowered whānau can make the most significant difference to intergenerational Māori health and wellbeing. Whānau empowerment will be shaped by access to quality information and advice, necessary resources, healthy living, a sense of agency and self-determination, and a conviction that the future can be created, not simply endured.
Mauri ora	Mauri ora seeks to shift the mauri (or life force) of a person from one that is languishing to one that is flourishing. A strong, flourishing mauri requires interventions, services and treatment that foster healthy lifestyles; increase knowledge and power; strengthen identity; encourage self-management; and restore dignity. Mauri ora has a spiritual dimension that recognises culture as a determinant of good health.
Wai ora	Wai ora acknowledges the importance of Māori connections to whenua as part of the environments in which we live and belong – and the significant impact this has on the health and wellbeing of individuals, whānau, hapū, iwi and Māori communities. An environment that is compatible with good health reflects the need for Māori to have access to resources (ie, good housing, safe drinking water, clean air, healthy food) and to live in environments that support and sustain a strong, flourishing mauri and a healthy and empowered whānau.